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# The Concept of an Early Intervention Center for Children with Disability and Developmental Delays

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## **Introduction**

The present Report is the result of year-long work in the research Project, supported by Open Society Institute.

Project objectives were:

- to develop a model of an early intervention centers for physically and mentally retarded children, promote early rehabilitation for such children and prevent their disabilities;
- to develop a policy paper on program strategies in the field of public medicine and health, in coordination with network mentors.

For the realization of these objectives the following operations were planned:

- Study of worldwide experience in methods of Early intervention into development of physically and mentally handicapped children.
- Creation of an information channel and information exchange with Early Intervention Network.
- Development of a public education program, organization of a continuous information campaign promoting the Early Intervention methods for prevention of disability, for early rehabilitation of handicapped children and their integration into social life.
- Development of methodological manuals for the center successful operation including information, educational and training program for parents of handicapped children and for specialists working with such children and their families
- Creation of a concept of an Early Intervention Center for physically and mentally handicapped children and their families in Kharkiv
- Publication of the methodological manuals

The Project was executed at the continuous cooperation with Dr.Agnes Lanyine and the organization support by Mrs.Pamela Kilpadi and Mrs.Olena Sidorenko. This enabled me the expansion of the professional communication circle and helped to set a contact not only with foreign specialists working in this field but to find adherents in Ukraine and Russia.

In the Report there are presentations of the Center Model (Part 1), the Policy Paper on Program Strategy (Part 2) and Financial Report (Part 3).

## **1. Model of the Early Intervention Center**

### **A. Basic Philosophy**

The main idea of the Project is the creation of the Early Intervention Center concept for children with physical and mental disabilities: prevention of their disabilities, early rehabilitation of such children, and their integration as well as incorporation into social life.

According to the project idea, we set ourselves two main questions.

1. What do the newness and attractiveness of Early Intervention system in Ukraine lie in?
2. In what way can we use the world's experience in order to create in Kharkiv the effective and humane helping system?

In the traditional approach the help is more focused on the “correction” and the try to make a child “normal”, than on the adaptation of an ill child to the environment or the adaptation of the environment to the handicapped children's needs. It is the principles of the Early Intervention, that let us see in each child his or her individual potential, give the children with developmental delays and children with disability the opportunity to overcome difficulties, maximally developing their abilities. They let us give such children a chance of complete or partial adaptation to the Society and show to normal or usual people the potential of such children.

Traditionally a child and a family are looked upon as an object of professional effect. The Early Intervention lets us use the family's own potential and energy, gives the parents an opportunity to be competent and equal participants of the rehabilitation process and to unite the efforts of all the interested sides – children, parents, specialists and the society on the whole.

A special interest in the early Intervention system represents the work with children at risk. This interest is caused by moral, ethic character as well as by social and economic ones.

Thus, the most important positions in the Early Intervention are as follows:

- Main goal of professional work is the complete or partial adaptation to the Society
- Principle of working in a team and involving the family into the team.
- Development of each child's potential and the usage of each family's resources
- Work with children with disability as well as children at risk.
- Work, starting from the earliest age.

## **B. Early Intervention Center (basic ideas)**

### *Mission of the Early Intervention Center*

To be a resource of help and support for both children and their parents and the one of professional training for specialists working with children with disability.

### *The Main Goals of the Center*

For children: to give children with disability and developmental delays an opportunity to overcome difficulties in their development, maximally develop their abilities in order to integrate into the society life either completely or partially.

For parents: to give them an opportunity to understand the essence of their children's problems, to see each child's resources, and become an active and equal participant in the rehabilitation process.

For society: to show it the disabled children's capabilities, their ability to develop, to prove a necessity of creating the system of assistance starting from the earliest age.

For professionals: to learn the new technology of helping children with disability, developmental delays and support of such families.

*The main direction of the Center*

*Dissemination of Information and Education on the Early Intervention, Research, Service.*

Dissemination of Information and Education on the Early Intervention:

- realization of informational and educational programmes for parents, specialists and the society about the modern opportunities of preventing children from disability and creating equal opportunities for them.
- training of specialists to work in the Center.
- popularization of methodological materials on helping the children with disability, developmental delays and on supporting their families.
- active use of mass media for the coverage of our activities.

Service:

- family therapy, provision of professional help for parents and children.
- creation and support of parents' self-assistance groups.
- adaptation or creation of assessment methods (developmental scales, psychological tests, remedial educational inventories).
- use of the child's ability profile as the starting point of the work

Research:

- putting of the Early Intervention methodology into practice.
- creation and development of the selection system for the children who need early intervention.
- creation and development of the assessment procedures for the children who need it.
- working out of the team's organizational principles.

*The Center exists to:*

- work with two categories of children those aged 0 to 6 years old: children at risk and the ones with disability of the same age.
- combine programs in the Center with home visits fulfilled by a team of professionals.

### C. Project Accomplishments and Outlooks

<b>Time frame</b>	<b>Project accomplishments</b>
November – December 1998	Creation of group «Early Intervention Center for Children with Developmental Delays and Disability» in Kharkiv. Elaboration of Group Statutes.
January 1999, April 1999	Presentation of the Project and group in Ministry of Health Care of Ukraine and regional department of Health Care.
January 1999	Observation of Early Developmental Center in Budapest
February- March 1999	Observation of the Early Intervention Network in St. Paul - Minneapolis region with the attendance of: <ul style="list-style-type: none"> <li>• Early Childhood Family Center (classes, home visits, parent groups);</li> <li>• Gillette Hospital (Gillette Children's Specialty Healthcare);</li> <li>• St. Paul Hospital (the program for premature children);</li> <li>• Medical Center (Courage Center);</li> <li>• Interagency meeting (discussion about interagency coordination actions).</li> </ul>
December 1998- April 1999	Establishment of contact with <ul style="list-style-type: none"> <li>• University of Minnesota, College of Education and Human Development ( Prof. Scott. R. McConnell);</li> <li>• International Society on Early Intervention (Dr. Michael Guralnick):</li> <li>• Early Intervention Network of Washington County -state Minnesota (Mrs. Melissa Wiger).</li> </ul>
March-April 1999	Three public lectures for medical specialists and psychologists about Early Intervention method.
March 1999	Observation of Budapest Autism Research Group work
May 1999	Meeting Ms. Helen Mess ( Program Coordinator of Kharkov-Cincinnati sister-city cooperation). Presentation of the Project.
May-June 1999	Creation of the work programme with the children's at risk mothers and signing of the agreement on the cooperation with City Perinatal Center.
June 1999	Development of the Program Home Visits and the starting of its realization
June 1999	Participation in the Mental Disability Advocacy Meeting
July up till now	Work in the City Perinatal Center with children at risk and their mothers
September	Meeting the representatives of the Cincinnati delegation. Discussion of the cooperation possibilities with Cincinnati Center for Developmental Disorders
September 1999	Creation of the interaction model – Early Intervention Center and the existing system in the field of helping children with disabilities in Kharkiv
September 1999	Participation in the Ukrainian-Germany conference in Odessa

October 1999	Participation in the symposium “Excellence in Early Childhood Intervention” in Vasteros, Sweden.
October 1999	Publication of the book for parents
October 1999	Discussion of the possibilities of cooperation with IRF
October 1999	Preparation of the documents for the registration of NGO Early Intervention Institute

The Project started in November 1998. The work on this project helped me to set contacts with International Society on Early Intervention, visit Early Intervention Centers in Budapest and USA, observation Early Intervention Network organization in Minneapolis and establish contacts with professionals in this area.

In January 1999 the Early Intervention Center Group was created, the base of which were doctors and psychologists with guest participation of other professionals. We have developed our working programme that has been adopted by the Ministry of Health of Ukraine. The statement on the cooperation between the group’s specialists and their American counterparts has been included in the Kharkov-Cincinnati memorandum on sister-city cooperation

The work on the research Project confirmed the acute necessity of practical work with real children and their parents, and creation of an operational Early Intervention Center in Kharkov.

We started practical work with children in July 1999 and it has been conducted at the Neurological Department of City Perinatal Center where children at risk with perinatal pathology of the nervous system and prematurely born are. They are aged between 10 days and 4 months. Now we render psychological support to mothers and members of families, perform a child’s development diagnostics and implement parents education informational program. This kind of help has been given to 95 families during 4 months (July – October, 1999). By now we have started home visits to two families.

In order to organize such a Center the Ukrainian Research Institute of Children and Juvenile Health Care Institute allocated us premises which need renovation and equipment to be put in.

The interaction schemes of the Early Intervention Center with the existing system in the city were created, the program of screening-diagnostics of the children’s development from the first year of their lives was suggested. And now it is being discussed with the City Health Care Department.

On the basic of the programme ‘Small Steps. An Early Intervention Program for Children with Developmental Delays’ (by Moira Pieterse and Robin Treloar with Sue Cairns), translated into Russian due to the efforts of the Dawn Syndrom Association (the city Moscow), instructional programmes for parents and specialists were created.

Thus, the research Project supported by OSI initiated the process of creation and development of the idea of modernizing service system in Kharkiv, which now



needs its organizational shaping – the creation of a working Center.

## **2. Policy Paper on Program Strategy**

### **A. Assessment of Context**

Nowadays various institutions and organizations existing in Ukraine dwell with the problems of handicapped children.

The analysis of the situation in the area of assistance to children with developmental delays and disability allowed to highlight a number of essential reasons causing their limited socialization.

1. The existing system of assistance to the children with delayed development aims at fighting its negative consequences and in most cases proves to be effective only when a defect has resulted in functional delays or disability, which makes its prevention more difficult.
2. Parents of the children with delayed development are often left alone with their problems. They are unable to provide timely and qualified assistance to their children with a view to preventing negative transformations.
3. Health service in this case is limited both to the increase of the social potential of the disabled children and to the development limits of their independence or full integration into a social life.
4. The disabled children become isolated from society as they stay either at home or in specialized establishments. They are unable to fully apply their potential and become productive members of society.
5. The Ukrainian society has not overcome ignorance, disrespect, prejudice and fear - social factors that hinder the development of the disabled children and lead to their isolation.

Therefore there is a need for new approaches and initiatives aimed at creating favorable conditions for the development of disabled children and insurance of equal opportunities for them. From this point of view the system of Early Intervention, which is widely used all over the world for prevention and early rehabilitation of the disability, is long-ranged as it proved to be humane, effective, and economically expedient.

Presently in Ukraine there is acute necessity to form a new policy in relation to disabled children and create a modern concept of providing help for such children in accordance with the Convention of the Child's Rights and the Standard Rules for Insuring Equal Opportunities for the Disabled. The principle of expansion of the integration of such children into society should be assumed as a basis for this policy.

The analysis of the existing context has shown both positive and negative factors.

The negative factors are the following:

- The traditional Ukrainian orientation towards ‘correction’ and attempts to make a disabled child ‘normal’, but not adapt such a child to the environment or adjust the environment to their needs. In this case, the help is aimed at removing negative consequences of disability, but not at developing each child’s individual potential. A handicapped child is regarded out of context of real life.
- The term ‘invalid’, as used in Ukraine, is not the same as the term ‘disabled’, as it is used all over the world. The reason for this difference is that an ‘invalid’ is a category of the medical disability model. Besides, Ukraine’s state help system (including special education, social support and medical care) is aimed at children who are ‘labeled as invalid’. Therefore, children with disability without this label do not fall in the existing help system (e. g. an autistic child doesn’t have label ‘invalid’).
- As a rule, various specialists (doctors, teachers, psychologists, social workers) deal with disabled children, but they work within the limits of the multidisciplinary approach. It is necessary to realize that a team is not a sum of specialists, but a completely different type of interaction.
- It should be noted that the tradition of institutionalizing disabled children is very strong in Ukraine. The reasons for this are the poor development of the community-based service and hard financial position of families with disabled children. This being the situation, the parents have to put the child into specialized institutions, as they are unable to maintain them and receive help directly home or at the place of residence.

However, positive tendencies in the approach to the integration of disabled children have begun to show off late.

- Organizations formed by parents of disabled children are establishing themselves more firmly. Such organizations enable parents to focus their activity on social rehabilitation of their children. According to unofficial data, at present there are 16 organizations of this kind in Ukraine. Besides, parents of disabled children often initiate the establishment of rehabilitation centers.
- Professionals who deal with disabled children come to realize that it is important to regard the integration of disabled children as the main result of work, but not only to offer specialized help. The necessity of teamworking with each child is being recognized. Examples of professionals working with parents on a partnership basis may be given.
- Presently the conditions are favorable in Ukraine’s Ministry of Health Care, which supports the search for and implementation of new ideas for providing help to disabled children.

The experience of foreign countries in giving help to disabled children has shown that the Early Intervention System meets the modern requirements set in the Convention of the Child’s Rights and the Standard Rules of Insuring Equal Opportunities for the Disabled.

In the Early Intervention System the disabled children integration principle is implemented in practice through:

- community-based service system;

- work with children at risk for prevention of disability;
- principle of a transdisciplinary team of specialists and the inclusion of the family in the team;
- development of each child's potential and use of each family's resources;
- providing help from a very early age;

## **B. Strategy: Goals and Results**

Considering the aforesaid, the creation of the Early Intervention System in Ukraine requires the solution of the following problems:

- creating of legal field for the development of Early Intervention (EI);
- formation of association of professionals for work in EI;
- influence on public opinion by changing public attitude toward disabled children;
- contribution to the formation of parents' self-help groups and interact with such groups on a partnership basis;
- creation of Early Intervention Centers and Early Intervention Network

### **1. Support of the Creation of the Legal Field for the Early Intervention (EI) Development**

It is necessary to create laws setting EI main objects and principles and regulating EI development issues (including financing) in Ukraine.

These documents should define who is entitled to help within the EI System.

It is essential to insure that not only disabled children, but also children at risk and children with developmental delays are users of EI, family-centralized service that is territorially close to the family and the child.

The EI system should be developed at all levels: local, regional, national. The EI principles should be adhered to at all levels, specific forms of implementing these principles may differ depending on regional and local conditions.

The participation of Ukrainian specialists in meetings with foreign partners should be supported so that they can familiarize themselves with the EI legal regulation system in different countries. Use of other countries' experience in this sphere will be surely helpful for implementing an effective and civilized process in Ukraine.

### **2. Support of the Formation of the Association of Professionals for Work in EI**

It is necessary to define what kind of specialists may work in the EI system. It should be borne in mind that it is possible to use the potential of existing professionals, working under Ministry of Health, Ministry of Education, Ministry of Social Protection (teachers-defectologists, doctors, psychologists, social workers), but only after they have received special training for work in EI. A team of trainers out of Ukrainian specialists should give such retraining and basic professional instruction for EI. In future EI may be studied as a discipline in higher educational establishments.

Special attention should be given to the information and methodological provision of specialists, publishing literature on EI (there is practically none at the moment), gaining access to the Internet, and establishing diagnostic procedures.

Criteria for quality of professional help should be established. Interaction between parents and specialists should be developed within the transdisciplinary approach using the service-coordinator model.

EI is a practical help system (service) and research. Therefore, it is necessary to support research into working out approaches that take local conditions, a cultural context into account to a maximum degree.

### **3. Support of Enlightenment Work with Public**

Information campaigns in mass media should show potential of disabled children, gradually eliminate the division of society on the basis of disability and develop mutual trust between various sections of society.

In enlightenment work programs demonstrating the EI potential for prevention of disability, reduction of consequences of disability and expansion of children's integration should be singled out.

It is necessary to support publication of brochures, information bulletins, popular literature on these issues for the general public.

### **4. Support of Parents' Organizations**

Interaction with parents' organizations on a partnership basis means that parents should be encouraged to actively participate in any activity connected with their children's needs, from forming a policy in relation to disabled children to evaluating specific programs. In the EI system parents are equal members of a team. They should be taught new models of interaction both with professionals and their children. It is necessary to provide educational training, orienting parents to the maximum development of individual abilities of their children.

### **5. Support of the Creation of the Early Intervention Centers and Early Intervention Network**

The creation of the Early Intervention Centers and Network requires taking the existing system of help to disabled children into account and insuring interaction (including financial) with state and non-state organizations that operate in this sphere.

The Early Intervention Centers' employees should visit homes, the object of these visits should be not only evaluation of the child, but their development. The centers should carry out programs of mass children development screening diagnostics to reveal those needing help in good time.

The Early Intervention Centers should be information and service ones for children and parents, and resource and coordination ones for specialists.

The long-term operation of the Early Intervention System is possible only with the state's participation in the process. The Open Society Institute mission consists of initiating, establishing and 'putting into orbit' the Early Intervention System in Ukraine.